

Stress Among Adults with Cystic Fibrosis (CF) and Their Loved Ones

Stress involves a variety of negative thoughts, feelings and reactions that accompany difficult situations. Everyone experiences stress as a natural part of life. However, adults living with CF, as well as their spouses, partners, or caregivers, face uniquely challenging circumstances and demands.

What Are Some Causes of Stress Related to CF?

Everyone's experience is unique, but some common sources of stress are:

- Exacerbations, hospitalizations, and medical procedures
- Clinic appointments and getting pulmonary function tests (PFTs)
- Time-consuming daily treatments
- Financial stress
- Disruptions to or limitations in engaging in school, work, or other valued activities
- Struggling with one's "place" in life or sense of life direction
- Dealing with uncertainty when considering the future, such as planning for education, employment, or family building
- Worry about disease progression and coping with advanced disease
- Balancing self-care and care for others
- Loss, grief, and "survivor's guilt"
- Not being able to access or benefit from breakthrough medications
- Low self-esteem and doubts about self-worth
- Developing and maintaining trust in yourself, your caregiver, your family, and your care team

What Are Some Signs of Stress?

There are many natural responses to stress, including:

- Emotions—feeling sad, anxious, overwhelmed, guilty, angry, or impatient
- Physical responses—feeling tense, restless, or fatigued, having stomach aches or headaches
- Thoughts—worries, difficulty concentrating, or self-critical thoughts
- Behavior—social withdrawal, difficulty completing tasks or self-care, using alcohol or other substances

What Can I Do to Help?

Emotional well-being is an important part of overall health. Here are some ways for individuals and families to practice emotional self-care and promote resilience for coping with stress:

- 1. Practice acceptance.** Situations that you and your spouse, partner, caregiver, or family may be facing are hard. It can be important to acknowledge and honor the feelings that you or others are experiencing before moving on to the next step to ask, *What can I do now?* Provide the space to share feelings while listening calmly and without judgment.
- 2. Break down problems and tasks into manageable parts.** Looking at a problem or task as a whole can feel overwhelming. Breaking it down can reduce stress, help you avoid procrastination, and lead to greater confidence.

9. Practice self-compassion. Are you being too hard on yourself? Many people notice that they are sometimes their own worst critics. **We all have bad days, and everyone is simply doing the best they can.**

Self-criticism drains energy and rarely motivates anyone to improve a situation. You can start practicing self-compassion by noticing the way that you talk to yourself. Self-critical thoughts can often appear in the form of should statements, such as *I should be doing better*. If you notice these types of thoughts, you can try asking yourself these questions: *Am I blaming myself for something that is not 100% in my control? Can I think about this in a way that is still realistic but is kinder to myself? (For example, I wish I was able to do this differently, but there are a lot of reasons that this situation is difficult that have nothing to do with me).* Consider how you would treat a friend in the same situation. What would you say to them? Use positive self-talk with the same love and support you would give to a friend. You can enhance this practice by writing down your self-critical thoughts; this can help create some mental distance from them. Then, try writing down the new, more helpful and less self-critical ways to think about a situation. Read your new statements aloud to yourself and see how they change the way you feel.

What Can My CF Care Team Do to Help?

Your CF team wants to support the emotional well-being of all individuals with CF and their caregivers. They understand that new challenges and concerns may come up, or old stressors can reappear from time to time. Communicate regularly with your CF team about what is going well, and what has been difficult.

If you, or a close caregiver such as your spouse, partner, or parent (even now that you are an adult) are experiencing symptoms of stress, anxiety, or depression that are persistent or interfering in CF care, school, work, or enjoying life, let your CF team know. Depression and anxiety are common and not surprisingly—given the additional stress that accompanies living with a chronic illness—more common in individuals with CF and caregivers. **The good news is that treatment for anxiety and depression works.** Your CF team can provide support and connect you with an appropriate referral.

In Case of An Emergency

If your level of distress is so high that you can't wait for a call back from your care team, please call 911 or go to your nearest emergency room. The following resources are also available via phone and online chat at any time:

The National Suicide Prevention Lifeline:

1-800-273-8255 or suicidepreventionlifeline.org/chat/

Your call is answered immediately and gets routed to a regional or local crisis center that is staffed with trained individuals who provide confidential emotional support to everyone who calls. **The call and service are both completely free.** You don't have to be feeling suicidal in order to use this service—it's for anyone experiencing emotional distress.

Crisis Text Line — Text HOME to 741-741